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ABSTRACT

The Carolina Policy Studies Program (CPSP) was established in October 1987 to track the implementation of Public Law 99-457, Part H (the law is now known as IDEA--Individuals with Disabilities Education Act), which aids states in providing comprehensive services to infants and toddlers with disabilities and their families. Since its establishment, the CPSP has used telephone interviews, document analyses, surveys, focus groups, literature reviews, and case studies to investigate the states' responses to Part H, resulting in 85 reports, journal articles, and book chapters. This report synthesizes CPSP findings concerning progress in implementation of Part H, in the areas of eligibility policy, family policy, personnel preparation, finance, interagency coordination, health coordination, and data systems. The report concludes that states are making impressive efforts to implement the complex law. The reform requirements of interagency coordination and parent empowerment were well accepted. Unsolved problems that remain include defining the role of the service coordinator, the limited efforts toward developing interdisciplinary training programs, and a lack of clear vision on how the program will be financed. An appendix lists publications produced by CPSP, in reverse chronological order by year of publication. (Contains over 50 references.) (JDD)

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# THE STUDY OF FEDERAL POLICY IMPLEMENTATION INFANTS/TODDLERS WITH DISABILITIES AND THEIR FAMILIES

## A Synthesis of Results

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# EXECUTIVE SUMMARY

In October, 1987, the Carolina Policy Studies Program was established at the University of North Carolina at Chapel Hill to carry out a cooperative agreement with the Office of Special Education Programs in the U.S. Department of Education. CPSP had a five year mission to track the implementation of Public Law 99-457, Part H -- a law to aid the states in providing comprehensive services to infants and toddlers with disabilities and their families. The law itself, now known as IDEA (Individuals with Disabilities Education Act), laid out in some detail *what* the states needed to do to respond to the law, but gave the states considerable latitude in terms of *how* they would structure these services and how they would carry them out. The law itself stressed reform in existing systems by encouraging family empowerment, service coordination, interagency cooperation, new models for personnel preparation, coordination of finance sources, and more effective data systems, among other provisions. It specifically wished to achieve service system reforms in terms of the direct service delivery (e.g., development of an Individual Family Service Plan), and reforms in the professional infrastructure (e.g., setting personnel preparation standards in ten disciplines).

## METHOD

CPSP investigated a variety of topic areas contained in the requirements of IDEA, including: personnel preparation, family empowerment, finance, eligibility, data systems, agency coordination, and health coordination. A variety of qualitative and quantitative methods were used to collect information on these issues from the fifty states. Included in the methodology were: structured telephone interviews, document analyses, surveys, focus groups, literature reviews, and case studies of six individual states. The final output from CPSP studies involved eighty-five full reports, short reports, journal articles, and book chapters.

## FINDINGS

### State Progress

Through the yearly administration of a comprehensive survey to Part H State Coordinators, it became clear that the states were showing steady progress and improvement in developing policies and having them approved at the state level. In the early administration, issues such as finance, interagency coordination, and data systems lagged behind some of the other areas in terms of policy development. From these reports, it was clear that some states would not make the five-year deadline originally stated in the law. As a result, Congress provided an additional two years to those states needing extra time to put the comprehensive service system into place.

The major barriers that slowed state progress in the implementation of Part H included: (1) the sheer volume of difficult policy decisions to be made; (2) the difficult financial situation that the states faced; and (3) a lack of direct authority or power to the lead agency, which resulted in time-consuming negotiations and compromise to achieve needed consensus.

### Eligibility

Each state was permitted by the law to establish their own specific eligibility requirements instead of following a detailed federal definition. The major questions asked about eligibility policy were: "What criteria were the states using for eligibility standards for infants and toddlers?" and "What were the states' plans for the optional

provision to include 'at risk' children?" A variety of surveys, telephone interviews, and document analyses revealed that the states had considerable difficulty establishing eligibility policies. Many states tried to identify a test or other instrument to determine eligibility. However, most states ended up using a combination of quantitative and qualitative criteria but still differed in the level of delay necessary to establish eligibility. Only a few states finally decided to include some form (biological risk, environmental risk, combinations, etc.) of "at risk" children in the eligibility policy. The reluctance to include "at risk" children, despite a widespread desire to do so, was clearly due to the financial difficulties in which the states found themselves and the large increase in financial support that would have to be found to provide comprehensive services.

**Family Policy**

The law clearly placed families at the center of a service system designed to be responsive to the child's and family's needs. Among the questions posed by CPSP were: (1) "What other federal laws and programs also affect infants and toddlers with disabilities and their families?" (2) "What are the states doing to design policies related to the case manager and the family?" and (3) "How did the states respond to the need to support families that deviated from classic patterns of family structure?"

Through on-site interviews in the state case studies, document analysis, and structured telephone interviews, CPSP was able to provide some answers to these questions. There were no fewer than twenty-five laws and programs that addressed, in some fashion, the same target population. Some additional analysis of how to synthesize these diverse efforts seems called for. The case manager or service coordinator required by the law remains a difficult role to define, with substantial differences being observed in the attitudes of health personnel versus social work and educational personnel on how such responsibilities should be distributed. The basic issue is, "Should the service coordinator be in executive control of services to be delivered, or be merely a coordinator of services provided to the family?"

CPSP studies indicated that there would be a substantial number of families from ethnic minorities and low socio-economic status that would be potential users of the comprehensive service system, but that states' policy development had not fully addressed the special needs of these groups.

**Personnel Preparation**

Two requirements for the states that IDEA presents are: (1) establish a system of personnel preparation and (2) develop standards for qualified personnel. Some of the policy questions posed were designed to determine: (1) the current status of personnel needs, (2) the willingness of institutions of higher education to respond to personnel needs, (3) the role that professional organizations play in the development of standards, and (4) what existing staffing patterns and problems were currently in place.

CPSP studies indicated major personnel shortages in fields such as occupational therapists, physical therapists, and speech language pathologists. The shortages were extreme enough to suggest that a restructuring of the service delivery system to take into account more support personnel would be called for, if full services are to be provided. Over 200 Deans of Schools of Education responded to a CPSP survey with lukewarm enthusiasm for initiating personnel preparation programs in their colleges and universities for young children with disabilities. They reported major barriers to such programs in terms of lack of funding and lack of qualified faculty or practicum settings. The Deans felt that additional financial support, an identifiable job market, and significant

state steps to demonstrate their commitments to such children (such as certification requirements) would encourage them to expand their efforts in higher education.

Representatives of professional organizations in the ten major fields affected by this legislation responded to surveys and telephone interviews that they would not establish separate standards for specialists in early childhood, but would provide descriptions of best practice and would try to incorporate more information on early childhood into their existing training programs and convention programs.

An additional CPSP study on state agency/higher education coordination indicated, through structured telephone interviews, that states showing progress in this area had structures and leaders that facilitated coordination. Some examples of these are a consortium of higher education institutions or key leadership personnel who stressed the development of processes for coordination and who generated a sense of trust between the state and higher education communities. Recommendations included a suggestion that states develop interdisciplinary consortiums to plan and implement pre-service and in-service personnel preparation efforts, and a search for diversity of financial sources to underwrite interdisciplinary personnel programs.

## Finance

The search for financial resources that would be significant enough to provide support for the comprehensive, multidisciplinary, interagency service system for infants and toddlers and their families is one of the most challenging of all requirements in this law. The major financial policy issues addressed by CPSP were: (1) "What options are available to the state in financing this program?" (2) "What are the states now doing to coordinate financial sources?" and (3) "What do the states see as potential future sources of funds for the program?"

In addition to the information gained from the six case study states, a fifty-state survey was conducted and expert opinion called upon to provide possible solutions to these financial issues. CPSP findings indicated that as many as 44 sources of funds were found in the fifty states, but that most states were focusing on three or four major sources of funding. Medicaid (at both the federal and state level), Title V of the Social Security amendments, and the Disability section of Chapter I were among those receiving heavy use.

States anticipated that they would use as future financial sources: Medicaid; the Early Periodic Screening, Diagnosis, and Treatment (EPSDT); private insurance; and the State Retardation and Developmental Disabilities Program. CPSP recommended that states continue to focus on Medicaid as a source for financing Part H services, but that, in addition, states would initiate special state funding for the program.

Additionally, CPSP recommended that a new federal approach to financing Part H should be developed, because the existing plan does not seem to be able to adequately fund the necessary services. One final recommendation was that all children judged eligible for Part H services should automatically become eligible for Medicaid funds, without a family income test. The high costs of services for children with multiple disabilities makes the "ability to pay" provision a mockery.

## Interagency Coordination

One of the mandates of the law was that there should be substantial interagency coordination to bring together the complex comprehensive service system from areas of

health, social service, education, psychology, etc. The policy questions posed by CPSP were: (1) "How did the Interagency Coordinating Council work to improve state agency coordination?" (2) "What kinds of structures and processes were the states using to facilitate coordination?" and (3) "What were the kinds and natures of interagency agreements that the states had entered into?" CPSP used the data from six state case studies, as well as a fifty-state survey, to gain information on these questions.

The case studies of the states and previous observations have indicated that Interagency Coordinating Councils are involved in the development of written policies, the acceptance and adoption of the policies within the states, and the facilitation of smooth operation of the service system.

The level of authority for the ICC in each state fell along a continuum from passive (where the ICC provided advice only) to very active (where ICCs actually acted as a board of directors with policy making authority).

The key to effective coordination was found in the cooperative approach of state program administrators, the willingness for some Part H staff to serve as liaison, and coordination structures at all levels of the service system.

In terms of structures for coordination, states that made substantial progress had strong leadership personnel with decision-making authority. Such leaders were accomplished in the art of negotiation and were described as "bridge builders" or "fence menders." The early structures and mechanisms for interagency coordination included task forces, committees with cross-agency memberships, and informal agreements made prior to formal documentation. Past experience within the state at interagency cooperation seemed to be a key factor in allowing this process to go forward with this particular law.

CPSP found widespread commitment of personnel in agencies in states throughout the country to implement the coordination aspect of Part H. Many states coordinated with other relevant programs (such as EPSDT). Some of the states coordinated efforts to serve at-risk children, as well. Interagency work groups and leadership groups across agencies were identified in over 75% of the states from the surveys.

## Health Coordination

Another significant issue is how to incorporate the health services with other Part H services. This is particularly an issue because limited Part H funds are accessible to those in the health community. Only health services necessary to allow the child to receive educational treatment or habilitation are approved for funding. Three major policy questions were posed by CPSP: (1) "What involvement do physicians have in planning for the implementation of the law?" (2) "What are the major forces preventing more effective coordination of effective health services?" and (3) "What are some options to the problem of cross-disciplinary cooperation?" Surveys and focus groups in five separate states helped to provide information to answer these questions.

The majority of the states had appointed a few physicians to the ICC. These physicians, in particular, helped to develop eligibility criteria. These physicians, when surveyed, felt that the major barriers to implementation included: low levels of funding, lack of interagency practitioner coordination, and lack of appropriately trained personnel.

Focus groups held in five states explored problems of coordination between health and other services. Three major themes were identified from the focus groups: the shortage of professional resources, a variety of family and social issues (e.g., poverty), and the importance of service coordination. A variety of frustrations with existing laws and health regulations were expressed. The service coordinator was seen by physicians as a decision-maker with regard to the treatment plan for the child and family. The second level of service coordination was that of a management coordination role, with direct and continuing contact with families. A series of experts on health policy commented on possible policy changes and stressed the importance of a series of structural changes that would lead to an increased formal system coordination. Several of the experts looked forward to a family-centered, community-based system of primary care that serves all children, one in which the health-care community can play an important role.

**Data Systems**

One of the mandated aspects of the law was the establishment of a data system. This was one of the components which the states were initially the slowest to implement into policy. CPSP explored the following questions: (1) "How were states planning to use data systems to improve program development?" (2) "How were local communities planning to use data systems to improve performance?" and (3) "How can data systems be used to ensure full participation by various societal sub-groups?" Surveys of eight states with existing data systems were used to answer some of the questions, as was analysis of existing demographic records. CPSP found that states were using their early intervention data systems to oversee local programs, automate the process of billing for services, and as an approach to meet federal report requirements.

It was encouraging that the states appeared to be using the data system requirement not just to fulfill federal reporting requirements but for a variety of ways to improve state and local decision making. A CPSP telephone survey of sixteen states found that only ten of the sixteen states collected information on ethnicity or race, and fewer than that collected income information, which meant that it would be difficult to tell whether certain ethnic, racial, or socio-economic groups were being shortchanged in terms of service delivery. CPSP recommendations were that: clients should be identifiable by race or ethnic background, family income (at least to 200% of the poverty line) should be noted, families should be identified by place of residence (through ZIP codes), and parental employment and insurance coverage should be noted.

## Discussion

CPSP staff found the "good faith" effort that states were making to implement this complex law particularly impressive. There seemed to be a strong sense in the professionals doing policy development that the changes in the law were long overdue and the reform requirements of interagency coordination and parent empowerment were well accepted. The basic problem was not in the will to make these reforms, it was in the skill to make them.

There remain a wide variety of unsolved problems, including: the role of the service coordinator, the limited efforts (so far) on developing interdisciplinary training programs, and a lack of clear vision on how the program will be financed. How these policies will operate in actual service delivery will be investigated by another child development institute financed specifically to address that problem.

## IMPLEMENTATION OF PART H POLICY

In October of 1986, the U.S. Congress passed a bill that provided states some modest planning and development funds to create a comprehensive, multidisciplinary, interagency service system for infants and toddlers with disabilities and their families. In October of 1987, the Carolina Policy Studies Program (CPSP) was established at the University of North Carolina at Chapel Hill to carry out a cooperative agreement with the Office of Special Education Programs (OSEP) in the U.S. Department of Education to track the implementation of that law, Public Law 99-457, Part H (now known as the Individuals with Disabilities Education Act -- IDEA). This final CPSP report will attempt to synthesize the various efforts of the Carolina Policy Study Program during a five-and-a-half year period, during which time it has produced 56 full reports, 18 short reports, and 11 journal articles or book chapters dealing with this law.

This law, IDEA, provided developmental funds to states that would agree to initiate a comprehensive service program for infants and toddlers with disabilities and their families. Such an expansive task presented a model of complexity. OSEP was rightly concerned about the implementation of this complex law in the 50 states. This was particularly true because previous comprehensive legislation for children with disabilities (Public Law 94-142) has had considerable difficulties in translating the intent of Congress into local action.

In the 1960s and the early 1970s, most of the legislation dealing with children with disabilities was content to provide additional resources for professionals so that they could do their jobs better. Accordingly, funds were made available for research, personnel preparation, establishment of demonstration programs, dissemination, and technical assistance. Little or no effort was made to change or modify the service system or infrastructure during that time.

In the last 15 years, however, federal legislation dealing with families having a member with disabilities has attempted to not only provide resources, but also to use the law as a vehicle for system reform. In the Education for all Handicapped Children Act (P.L. 94-142), there was a clear mandate for zero reject, individual education plans, due process, and other elements indicating that lawmakers were interested in changing, transforming, and reforming current educational practices.

Similarly with IDEA, there was substantial indication in the legislation itself that legislators wished to see programs for infants and toddlers with disabilities and their families encourage family empowerment, service coordination, interagency cooperation, new models of personnel preparation, and more effective data systems for reporting purposes. Interestingly enough, while the law went to some lengths in terms of instructing the states who wished to participate about <u>what</u> it was that they were to do to respond to the law, it gave states considerable latitude in terms of <u>how</u> they would propose to do it, and how they would propose to carry these requirements out.

Table 1 indicates the 14 specific components of the for a statewide, comprehensive system that the law placed on each of the states. The federal government was prepared to provide four years for the states to gear up for the implementation of a comprehensive, multidisciplinary, interagency system of services for this population.

The need for this particular legislation became evident following the implementation of P.L. 94-142. This law, inappropriately named the Education for All Handicapped Children Act (because it did not include children from birth to age three), revealed a substantial gap in the pattern of service delivery to children and families. In

# Table 1

## Minimum Components of a Statewide Comprehensive System for the Provision of Appropriate Early Intervention Services to Infants and Toddlers with Special Needs

[P.L. 99-457, Sec. 676(b)]

P.L. 100-147

1. Definition of developmentally delayed.
2. Timetable to all in need in the state.
3. Comprehensive, multidisciplinary evaluation on needs of children and families.
4. Individualized Family Service Plan and case management services.
5. Child find and referral system.
6. Public awareness.
7. Central directory of services, resources, experts, research and demonstration projects.
8. Comprehensive system of personnel development.
9. Single line of authority in a lead agency designated or established by the governor for carrying out:
   a. General administration and supervision.
   b. Identification and coordination of all available resources.
   c. Assignment of financial responsibility.
   d. Procedures to ensure services are provided and to resolve intra- and interagency disputes.
   e. Entry into formal interagency agreements.
10. Policy pertaining to contracting or making arrangements with local service providers.
11. Procedure for timely reimbursement of funds.
12. Procedural safeguards.
13. Policies and procedures for personnel standards.
14. System for compiling data on the early intervention program.

addition, there has been continued and accelerated interest in the importance of the early childhood years and a realization of how important those years were to the developmental progress of children. Finally, there was a recognition of the impact and stress placed upon the family unit by the presence of a child with disabilities in the family, with both a potential traumatic influence upon the initial discovery and continued stress and conflict within the family due to the daily concerns of the family (Sameroff & Chandler, 1975; Gallagher, 1992a; Lazar & Darlington, 1982).

All of these factors combined to lead key legislators (Senator Weicker of Connecticut being an outstanding example) to press for a law that would provide services from birth on for children with disabilities and their families.

## Policy Development

This law proposes a wide ranging set of changes in how services are delivered and how professionals interact with their clients and with each other. The reforms proposed in the law IDEA take two different forms. The first set of reforms deals with direct service delivery to children and families. From Child Find, through the development of the Individual Family Service Plan, to the mandatory case manager (now referred to as "service coordinator"), to evaluation, the various stages of service delivery are touched upon by this law.

The second set of reforms deals with the professional and organizational infrastructure that undergirds the service delivery. The law shows concern for the elements of the underlying infrastructure such as: personnel preparation standards so that quality personnel are available to delivery the services; data systems that can provide important information regarding program effectiveness and coverage; interagency coordination to provide resources from many different disciplines and organizations, and finance sources to assure effective financial underpinnings for the overall program.

The infrastructure is often hidden from the client (the family), whose concerns are mainly directed to the relationships between themselves and the professionals that they are in direct contact with, but it nevertheless becomes a critical element in program quality. If any one of the major dimensions of the infrastructure breaks down, then the possibility that there will be quality services becomes significantly less.

**Method of Analyzing Policy Development**. Figure 1 indicates the topics and the strategies that were followed in conducting the variety of policy studies in CPSP. The topics follow the major segments of the legislation, with the first topic -- state progress -- being an attempt to provide an overall assessment of progress made toward full implementation by each state. This was largely done through periodic surveys of each state coordinator.

Specific topics, such as personnel preparation, family empowerment, and finance, were investigated through a variety of qualitative methods. As can be seen in Figure 1, the state case studies focused primarily on three dimensions: family empowerment, finance, and agency coordination. Six states were chosen on the basis of multiple criteria and were visited by a team of investigators who interviewed and collected documents. Five of the six states were visited a second time approximately a year after the first visit.

Telephone interviews provided an effective and inexpensive way of collecting a large body of information on topics such as data systems and personnel preparation, while document analysis tended to provide specific information regarding how the states were planning to deal with issues such as eligibility. Surveys played a significant role in the

**Figure 1**

## Policy Studies Methods and Products

### Carolina Policy Studies Program

| Topic | State Case Studies | Phone Interviews | Document Analysis | Surveys | Focus Groups | Literature Reviews | Full Reports | Short Reports | Journal & Book Chapters | |
|---|---|---|---|---|---|---|---|---|---|---|
| State Progress | X | | | XXXX | | X | 7 | 2 | 3 | |
| Personnel Preparation | | X | | | X | X | 9 | 5 | | |
| Family Empowerment | X | X | | X | | X | 17 | 2 | 1 | |
| Finance | X | | X | X | | X | 4 | | | |
| Eligibility | | X | X | X | | X | 5 | 2 | 1 | |
| Data Systems | | X | X | X | | X | 1 | 1 | | |
| Agency Coordination | X | | | X | | X | 4 | 1 | 2 | |
| Health | | | | X | X | X | 3 | 4 | | |
| Other | | | | X | | X | 6 | 1 | 4 | |
| | | | | | | TOTALS: | 56 | 18 | 11 | = **85** |





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CPSP reports, as did literature reviews, which were conducted for practically all of the major areas. The emphases of CPSP showed clearly in the number of reports produced, with the topics of family empowerment, personnel preparation, and agency coordination receiving continuing attention. The full listing of reports produced by the Carolina Policy Studies Program can be found in the Appendix to this final report.

**State Progress in Policy Development**

One of the early actions of the Carolina Policy Studies Program was to pursue, with the states, the progress that they were making in implementing the various dimensions of Public Law 99-457, Part H. A survey was designed to measure the progress across the 14 key elements of state responsibility (See Table 1).

The survey was administered four times during the length of the project -- the first time in 1988 and yearly after that. The survey was designed to answer three questions: (1) "To what extent has the state reached full implementation of the 14 components required?" (See Table 1); (2) "Which elements are proceeding more rapidly than others to full implementation?"; and, (3) "Which states differed in their rates of implementation?"

Through all four of the reports (Harbin, Gallagher, & Lillie, 1989; Harbin, Gallagher, Lillie, & Eckland, 1990; Harbin, Gallagher, & Lillie, 1991; and Harbin, Gallagher, & Batista, 1992), the states showed continuing progress toward their goal of full implementation. There were substantial differences among states in the total amount of progress that was being made, and in progress being made within the components themselves. The areas that seemed most difficult to write policy for were finance, data systems, and (during the first two years) interagency agreements.

The difficulties that slowed state progress toward implementation were identified as follows:

1. The sheer volume of difficult policy decisions required of the states;

2. The difficult financial situation in which many states and the federal government found themselves;

3. A lack of direct authority or power for any one source (such as the lead agency) to require other agencies to participate and contribute. This resulted in the time-consuming process of negotiations and compromise;

4. Many of the policy areas required novel and creative solutions. The creation and acceptance by others of these solutions was also time consuming.

From one year to the next, there was a high correlation in terms of the progress being made on the fourteen components. That is, finance was far down the list of implementation and continued that way for all four years. The great range of individual differences in state progress led the Carolina Policy Studies Program to recommend that states having special difficulty progressing should be allowed two years of additional planning. In the last report of state progress, from Harbin, Gallagher, & Batista (1992), the authors continued to note that there were a small group of states that are having continued difficulty even though the states in the aggregate have shown a "good faith effort" in continuing to press forward toward a complicated goal.

One of the other questions posed by the study was whether some factors could be identified that were related to state progress in implementation of the law. Various

dimensions were examined, including the prior history of early childhood services, the available resources, the wealth of the state or geographic region. None of these factors appeared to have a significant influence on policy development. The key factor that did seem to have some relationship to progress was the prior availability of institutional structures within the states that made these collaborative efforts (Harbin, Gallagher, & Lillie, 1991; Harbin, Gallagher, Lillie, & Eckland, 1990).

The realization that many of the policy decisions taken by the state committees and task forces were based on personal values that often went unrecognized (see Gallagher, 1991) led the CPSP to commission a Handbook for Ethical Policy Making (Paul, Gallagher, Kendrick, Thomas, & Young, 1992). This handbook was designed to provide decision makers with some insight into the role that individual values play in making choices and decisions. This handbook, distributed to ICC chairs and Part H Coordinators, provided a model for ethical decision making.

**Eligibility**

Sec. 672

*The term "handicapped infants and toddlers" means individuals from birth to age 2, inclusive, who need early intervention services because they:*

*(A) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: Cognitive development, physical development, language and speech development, psychosocial development, or self-help skills; or*

*(B) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.*

*Such a term may also include, at a State's discretion, individuals from birth to age 2, inclusive, who are at risk of having substantial developmental delays if early intervention services are not provided.*

One of the major requirements spelled out by this law is that states should establish a definition as to which infants and toddlers will be eligible for services. The federal government was following its particular style in this law of determining *what* the states should do, but not *how* they should do it. The federal government, for example, is not providing a federal definition of children with disabilities that states are mandated to follow. This raises the interesting prospect that there could be 50 different definitions and different eligibility standards. This, among other things, would make a descriptive portrait of who is being served difficult to develop on a nationwide basis.

There is a subtle mix of professional and technical problems to be found with establishing eligibility, along with some particular political problems facing the states. In terms of the professional problems, there are few instruments that can be used with great reliability in this age range. Even if one settled upon the instrument to be used, the question would remain of how far from the "average" the child must be in developmental processes before they are declared eligible.

The political issues come to the fore when one views the optional "at-risk" category. Including an at-risk group raises the prospect of a greatly expanded population to be served and a consequent increase in cost.

**Policy Questions on Eligibility**. The major questions that were pursued by the Carolina Policy Studies Program with regard to eligibility were:

1. What are the definitions settled upon by the states for developmentally delayed children?

2. What are the states' standards and parameters for the "established condition" section?

3. What are the states doing about the optional at-risk category?

4. What instruments or procedures are being proposed for the determination of eligibility?

5. Is there discontinuity between the eligibility policies for infants/toddlers and preschool children with disabilities?

In 1991, the Carolina Policy Studies Program conducted an analysis of 49 of the states' eligibility policy documents. Finally, in 1992, documents were solicited from the states that dealt both with the infants and toddlers section and the preschool section, so that a comparison of possible discrepancies in the definitions could be identified. Also, a separate study was conducted on analyzing the current status of states' eligibility policies for children with disabilities aged 3-5.

**Eligibility Results**. Although the language that the states used in creating a definition mirrored closely the language in the law itself for developmental delay and established risk conditions, states differed substantially in what they saw as the specific criteria that would be used to determine eligibility.

The earliest study on the states' progress toward developing a definition (Harbin, Terry, & Daguio, 1989) revealed great variance in the states in the level of delay needed to be considered eligible. Some states utilized percent delay, but even then the range went from 20% to 50% delay in one or more developmental areas. Other states used standard deviation or "months delayed," and the requirements for eligibility in those states also varied widely, from 1 standard deviation to 2 standard deviations delay. The early study also found that the task for developing a definition was handled by a task force or, in some cases, the interagency coordinating council.

There was also extraordinary variance in those states attempting to consider at-risk as an additional characteristic. Some states used biological at-risk factors only; others used environmental at-risk factors only; some states used a combination of both. The early study, in particular, found that the draft definitions did not recognize the concept of multiple and cumulative risk, or that the number of risk factors would seem to be more important than the presence of any one risk factor.

Two years later (Harbin & Maxwell, 1991), a further analysis of 49 state eligibility policy documents was carried out. This analysis found continued variance among states on the specific criteria for determining eligibility of developmentally delayed children. Sixteen states used test-based criteria only; four states used professional judgement or documentation of atypical development; in twenty-two states, a combination of test and non-test criteria were used. Thirty-nine of the Forty-seven states included a list of specific conditions under the category of "established conditions." However, among these states there was relatively little agreement of which specific conditions constituted eligibility.

At the time of the study, 20 states were considering including at-risk children in their definitions, with 15 of these 20 including both biological and environmental risk factors. In the earlier study, it was determined that eligibility was primarily test-driven. In addition, there was little agreement across states on the criteria for eligibility, there was continued confusion between "established conditions" and "biological risk" conditions, and states were using a single risk factor instead of multiple risks for the at-risk category. Many of these problems remained two years later, although there seemed to be some drawing together and recognition, by the states, of the importance of clinical judgement to supplement test data and information.

The CPSP study on eligibility policy for preschool children (ages 3-5) revealed a changing set of eligibility policies (Harbin, Danaher, Bailer, & Eller, 1991). In reviewing the policies for the 50 states and the District of Columbia, Harbin, et al., found that 20 of the states were still using a categorical approach; six were using a non-categorical approach; 25 others were using a combination of the two.

The states were concerned with <u>false positives</u> -- that is identifying children as having handicapping conditions who really do not (this results in a waste of scarce resources). They were also concerned with <u>false negatives</u> -- when children with a handicapping condition are not identified as such and thus go without necessary services. The attempt to reach an effective middle ground has caused the states to engage in a wide variety of policy adjustments, involving both quantitative and qualitative criteria. Some states are using percent delay as quantitative criteria, while others are using standard deviation on typical measures. What was most evident from this analysis is that many states are rethinking their eligibility criteria and their development of policy is continuing to evolve.

As infants and toddlers with disabilities enter preschool programs, there has been increasing concern about problems related to the transition period from Part H to the Preschool programs at age 3. Harbin, Danaher, & Derrick (1992) looked at the potential transition issues that face children and families moving from one set of program rules to another. Specifically, would children included in the infant and toddler program under the "at-risk" provision lose services under a different set of definitions at the preschool level? Would there be differences in who would be judged eligible in those states where Part H uses a non-categorical approach and the preschool program uses categorical definitions? Finally, would there be differences between the infant/toddler and the preschool programs with respect to the level of delay required for eligibility (For example, 25% delay in the infant program; 50% delay in the preschool program)?

In this study, the focus was again on document analysis, in which the two sets of definitions were examined. The results of this analysis were that 24 states were found in which infants and toddlers eligible under Part H would probably or certainly remain eligible under Part B (the preschool law). In 27 other states, however, there appeared to be one or more of five areas of concern regarding the continuity of eligibility as of the date of this report. These areas of concern were:

1. The inclusion of at-risk children in the infant/toddler program but not in the preschool program,

2. Preschool criteria that required a higher level of delay or disability for eligibility,

3. The use of professional judgement as the sole criteria for infant/toddler eligibility instead of the categorical or quantitative approach used in preschool,

4. The incompatibility of different scoring procedures and instruments used in the infant/toddler and preschool programs, and

5. The possible elimination of some disabilities that are difficult to document using test scores.

Eleven of the states had one of these five problems, while 13 states had two. Only three of the states had three of these concerns related to continuity. Nineteen of the states reported a problem with preschool delay levels being at a higher criteria level than the infant/toddler program; ten states reported problems with the infant/toddler at-risk category. There appeared to be a "good faith" effort by the states to come to some accommodation here, and that accommodation is made easier if the Part B criteria are flexible or include professional judgement as part of the criteria process.

Overall, the states have devoted an enormous amount of time and professional expertise on this eligibility issue. On the other hand, it has probably moved some of the states from a prior dependence on categorical and quantitative measurements to the inclusion of clinical judgement as a standard. The quantitative and categorical approach, when used exclusively, would likely miss some eligible infants and toddlers. This, in turn, has caused many of the states to rethink their preschool eligibility policy, as well. It is doubtful that the framers of this legislation realized the degree to which the issue of eligibility was going to become a major effort on the part of the states. It is also unlikely that they imagined how the "at-risk" category would generate such political heat at the state level.

One of the most innovative -- and scientifically valid -- provisions of Part H was the allowance that states could include infants and toddlers who were "at risk" for developing disabilities during the first three years of life among the children who were eligible for services. According to our information, about half of the states originally planned to take advantage of that provision (Harbin & Terry, 1991), but only about ten states eventually included high risk children in their final eligibility policy. At CPSP, we believed that many states, assuming that all services would be automatically provided for all at-risk children, considered the potential price tag too great. CPSP proposed (Gallagher, 1993) that the regulations would allow for:

> IDENTIFICATION AND PERIODIC MONITORING OF INFANTS AND TODDLERS JUDGED TO BE "AT-RISK" FOR DEVELOPING A DISABILITY. A FULL RANGE OF SERVICES SHOULD BE MADE AVAILABLE FOR CHILDREN WHO SHOW EVIDENCE OF DEVELOPING A DISABILITY.

If such a provision applied, costs would be limited to periodic screening of this population, except when serious consequences could be observed that required broader treatment. We believe that such a provision would encourage many states to reconsider the inclusion of "at-risk" children.

**Policy Development for Families**

*Sec. 676 (b) (3):*

> *"The state wide system shall include. . .*
> *(3) a timely, comprehensive, multidisciplinary evaluation of the functioning of each handicapped infant and toddler in the State and the needs of the families to appropriately assist in the development of the handicapped infant or toddler,*

*Sec. 677 (a):*

*Each handicapped infant or toddler and the infant or toddler's family shall receive. . .*

*(d):*

*(2) A statement of the family's strengths and needs relating to enhancing the development of the family's handicapped infant or toddler,*

*(3) A statement of the major outcomes expected to be achieved for the infant and toddler and the family, and the criteria, procedures and timelines used to determine the degree to which progress toward achieving the outcomes are being made and whether modifications or revisions of the outcomes or services are necessary. . .*

*(6) The name of the case manager from the profession most immediately relevant to the infant's and toddler's and the family's needs who will be responsible for the implementation of the plan. . .*

*Sec. 680 (Procedural Guidelines):*

*The statewide system shall provide. . .*

*(1) The timely administrative resolution of complaints by parents.*

*(2) The right to confidentiality of personally identifiable information.*

*(3) The opportunity for parents and a guardian to examine records relating to assessment, screening, eligibility determinations and the development and implementation of the individualized family service plan.*

One of the significant additions to legislation in the past two decades has been the increasing emphasis on the importance of the family. Part H of IDEA is one of a large number of laws passed to help children with special needs that have stressed parental empowerment and have encouraged and mandated professionals to provide as much support as possible to the family unit (O'Reilly, Place, & Anderson, 1990a, 1990b, 1990c, 1990d, 1990e, 1990f). The law is clearly written to strengthen the role played by parents in planning and executing services for their child. The assumption is that the more parents invest personally in the program, the more interest they will take in their child's progress. A similar assumption is that a parent who is in charge of one's own life situation is more effective than one who is a passive player waiting for someone else to do something about difficult situations (Gallagher, 1992b).

Some of this change from an exclusive emphasis on the child to concern for the family has undoubtedly emerged from the frustration over limited developmental gains that can be made through direct intervention with children alone. It also comes, in part, from of a growing understanding of the powerful effect of the social ecology surrounding the child on the child's eventual adaptation. There has also been increasing evidence that meaningful changes can be obtained by increasing family parenting skills and helping the family through various types of emotional support (Gallagher, 1990).

Consequently, the Carolina Policy Studies Program placed substantial emphasis on the study of emerging policies related to the family in Part H of IDEA. Some of the major family policies questions were:

1. What other federal laws and programs exist affecting infants and toddlers with disabilities and their families?

2. What are the states doing to design policies related to the case manager (service coordinator)?

3. How are the states designing policies to protect the family and the family's interest through procedural safeguards?

4. How are the states responding to the need to support families that deviate from classic patterns of family structure and cultural values?

**Methods for Families**. A variety of methods were used to collect information related to family policy. These included: surveys of the 50 states, six state case studies involving on-site interviews with key public and private sources, document analyses, and structured telephone interviews. As was the case with other policy studies, the information collected here is time-bound. The states were in a process of developing policy, but many of the states had not completed their discussions or their final judgments on what the appropriate policies would be on a variety of issues. The dates of these reports, therefore, become important when assessing the progress that states were making on this important area.

**Federal Family Policy**. Although those professionals deeply concerned with the implementation of Part H pay close attention to the language of the law and the subsequent guidelines, they may ignore the fact that there are a wide variety of other federal provisions for infants and toddlers with disabilities. Accordingly, the Carolina Policy Studies Program conducted a series of analyses of existing federal laws that related to these populations. The findings from these studies are divided into six reports, each focusing on one of the following topic areas: identification and evaluation, individualized service plan, case management services, parent training, procedural safeguards, and advisory councils (O'Reilly, Place, & Anderson, 1990a, 1990b, 1990c, 1990d, 1990e, 1990f). Twenty five laws and programs were identified that addressed the same target population -- infants and toddlers with disabilities and their families -- and were explicitly addressed to either education, health, or human services.

Examples of some of the laws and programs noted would be:

* Chapter 1, Part A (financial assistance to meet special educational needs of children)

* Basic programs operated by local educational agencies

* Bilingual Education Act, Part A

* The Developmental Disabilities Assistance and Bill of Rights Act, Part B

* The Public Health Services Title XIX, Part B

* The Alcohol, Drug Abuse, and Mental Health Services Block Grant

* The Child Abuse Prevention and Treatment Act

* The Public Health Services Act, Section 330 (Community Health Centers)

- Social Security Act, Title V
- Maternal and Child Health Block Grant

In analyzing these 25 programs, CPSP found the following:

- Thirteen of the programs had provisions for identification and evaluation.
- Nine of the programs had provisions for Individualized Service Plans.
- Seven of the programs had case management services.
- Twelve of the programs involved parent training.
- Nine of the programs mentioned procedural safeguards.
- Six of the programs had advisory councils similar to the ICC.

These other laws and their associated regulations and guidelines can provide some extra guidance for state policy makers in terms of how other agencies and programs have tried to meet issues such as procedural safeguards or case management.

**Service Coordinator (Case Manager)**. One of the clear indications of concern by the framers of the law for families is shown in the development of a case manager or a service coordinator role. This individual is charged with the responsibility of coordinating the professional services involved so that the family has a single point of contact to the helping professions. The family also has this coordinator to be their advocate in the services domain.

Although there was the usual diversity among states regarding their approach to policy statements on this topic, some general themes could be identified (Place, Anderson, Gallagher, & Eckland, 1991). There seemed to be a strong majority of states planning to use an interim case manager to help the client through the referral and assessment process. At that point, the operational case manager, or the service coordinator, would be assigned by the IFSP team. In many of these states, there was an expectation that the family would have a role in choosing the service coordinator.

With regard to the level of preparation and training for case management, many of the states saw this person as having a Bachelor's or -- at most -- a Master's degree. The reader will note that this is in substantial disagreement with the discussion of the role of the service coordinator in the health coordination area, which sees the case manager as in executive control of the case, as well as a convener of meetings, etc. Some considerable diversity was also indicated in terms of how states proposed to finance the required service coordination. Over half of the states planned to use existing state funds, but a number of other states are investigating the use of Medicaid for this purpose. Still other states plan to use some of the Part H funds for this purpose.

It is clear that on this, and many other provisions of the implementation of this law, that subsequent experience with the concept of service coordination will inevitably result in modification and refinement of the procedures necessary to effectively deliver services to the family.

**Procedural Safeguards**. Part of the commitment to family empowerment involves some specific statements related to the rights of families and their child. Seven specific procedural safeguards are noted in the Part H language:

1. The timely administrative resolution of complaints by parents and the right of any party to bring civil action with respect to the complaint.

2. The right to confidentiality of personally identifiable information.

3. The opportunity for parents or guardians to examine records related to assessment, screening, eligibility, and the development and implementation of the Individualized Family Service Plan.

4. Procedures to protect the rights of infants and toddlers with handicaps, whenever the parents or guardians of a child are unknown or unavailable (this includes the assignment of a surrogate parent).

5. Written prior notice to the parent or guardian related to the initiation or change, or refusal to initiate or change, the identification evaluation placement, or provisions for early intervention services.

6. Procedures to ensure that the written notice fully informs the parent or guardian of all available procedural safeguards.

7. The child shall continue to receive services during the processing of a complaint or proposed changes in procedures.

At the time of the report (Place, Gallagher, & Eckland, 1991), the states had been slow in developing specific policies related to confidentiality, family access to records, etc. These issues appear to have been put aside in favor of some of the more pressing issues related to eligibility, finance, etc. The surveys and the case studies also indicated some degree of dissatisfaction with existing procedural safeguards and a desire to craft a set of policies that would improve them. Among the difficult issues largely unresolved at the time of the study were how to force compliance from agencies that are showing a marked reluctance to cooperate.

**Culturally Diverse Families**. One of the substantial challenges to policy makers at the state level was how to craft a set of policies related to service coordination, procedural safeguards, and Individual Family Service Plan, that would fit the needs and requirements of the diverse family populations in this program. Arcia, Keyes, Gallagher, and Herrick (1992) reported on an analysis of data from the 1991 Current Population Survey conducted by the U.S. Census. The authors examined the distribution of factors that might interfere with family access to -- and use of -- services, including: poverty, maternal employment, ethnic minorities, large family size, low maternal education, and teen motherhood. For families with children under five years of age, they concluded that at least 20% of all young minority children and their families would have as many as three factors that have been associated with service underutilization. Only 7 out of 100 children would have none of the factors that would seem to be a barrier to accessing services. The findings of this study raised the issue of what can be done to design policies to make sure that the 93% *with* factors identified as barriers would receive necessary services.

The policy study recommended a variety of specific provisions that go beyond the general-purpose family policy statements of many of the states. For example, public awareness campaigns should specifically target minority populations, and an extensive child

find and referral system should be instituted to reach populations that may be underserved. Transportation should be provided as needed to ensure that services are accessible. Costs of services should be minimized to make them accessible to all families, particularly the working poor who do not qualify for Medicaid and are not covered by insurance. Families should be able to choose times for meetings and services so as not to interfere with their work schedules. A series of other, more specific, stated policies to help families who are culturally different or economically disadvantaged obtain equitable availability, accessibility, and appropriate of services are outlined in the report.

Accordingly, the CPSP made the following recommendation (Gallagher, 1993):

> POLICIES DEALING WITH FAMILIES THAT CAN BE DESCRIBED AS "TWICE IN NEED" SHOULD BE SPELLED OUT IN MORE DETAIL, WITH AN EMPHASIS ON INTERAGENCY COORDINATION TO ENSURE NEEDED SERVICES TO THE FAMILY. STATE DATA SYSTEMS SHOULD INCLUDE ETHNIC, RACIAL, AND INCOME DATA ON FAMILIES TO ENSURE THAT ALL ELIGIBLE FAMILIES ARE BEING SERVED.

One of the encouraging features of the policy studies on families was a general willingness on the part of professionals to involve families in decision-making. When there were differences of opinion within a state, they centered around how to choose the appropriate mechanism to encourage family participation. There appeared to be a minimum of professional resistance to most of these changes and a general acceptance of the central role to be played by the family. At the present time, most of the states appear to be making a strong "good faith" effort to meet the requirements of the law with regard to family policy.

**Personnel Preparation**

*Sec 676 (b)*

*(8) A comprehensive system of personnel development*

*(13) (A) The establishment and maintenance of standards which are consistent with any State-approved or State-recognized certification, licensing, registration, or other comparable requirements...*

*(B) To the extent such standards are not based on the highest requirements in the State applicable to a specific profession or discipline, the steps the State is taking to require the re-training or hiring of personnel that meet appropriate professional requirements in the State*

It is clear to one and all that the success of this program depends heavily on the presence of highly qualified personnel to deliver the essential services to infants and toddlers with disabilities and their families. Without the design of effective service systems and the execution of service delivery by well-prepared professionals and paraprofessionals, the rest of the structure of the program and the intent of the law itself can easily be frustrated. That is why the framers of the law wrote 2 of the 14 state requirements in personnel preparation : the setting of professional standards and the design of a comprehensive system of personnel development.

Yet the call for professional standards and a comprehensive system of personnel development quickly encounters large complexities and impressive state diversity. Of the ten professional disciplines that are expected to play a key role in this comprehensive service system, each has its own traditions, standards, and models of personnel preparation.

In institutions of higher education, for example, the training for such professionals can be found in schools of Medicine, Nursing, Social Work, and Education, in addition to individual departments such as Maternal and Child Health, Psychology, Special Education, etc.

A wide variety of policy questions were executed in this area by the Carolina Policy Studies Program. The following questions were posed:

1. What is the current status of personnel needs to meet the demands of P.L. 99-457, Part H?

2. How will institutions of higher education respond to the personnel preparation requirements of Part H?

3. What role will professional organizations play in the development of programs of personnel preparation for infants and toddlers?

4. What are some existing staffing patterns and problems in early childhood programs?

5. What is the role of federal agencies in encouraging personnel preparation?

6. How can coordination between state agencies and higher education institutions be facilitated and increased?

7. Are there some existing personnel preparation models for pre-service, in-service, and leadership training in some states that can provide guidance to other states?

8. How can a comprehensive, statewide, in-service training program be established for Part H?

**Shortages of Personnel**. To answer the question of the potential personnel needs in the field of infants and toddlers with disabilities, the Carolina Policy Studies Program investigated the situation in three of the ten professions likely to be involved in the legislation: occupational therapists, physical therapists, and speech/language pathologists (Yoder, Coleman, & Gallagher, 1990). The study attempted to establish the existing supply of these three professional groups and to project the number of personnel needed to serve the population from birth to age three and then to calculate how many additional professionals would be needed to meet the demands of full implementation. The needs and shortages presented in the report were based upon various manpower studies in each of the three professions and were matched against a proposed desired ratio of professional to client, in order to determine projected needs.

The study disclosed a substantial shortage of personnel in all three of these areas across the board in addition to the special area of infants/toddlers. Along with those shortages has been a documented decline in personnel preparation programs in speech/language pathology. There was little evidence to suggest that there will be a substantial expansion in any of these fields in the near future in terms of personnel preparation.

Using the current models of service as a guideline, it is unlikely in the extreme that there will be sufficient professionals prepared to work with infants and toddlers in the foreseeable future. While major attempts should be made to strengthen existing personnel preparation programs, it seems clear that some modification of current service delivery models will be necessary. This might include the effort to increase the number of licensed

OT and PT assistants and also to move toward a type of holistic approach or a trans-disciplinary approach toward developing habilitation services for infants and toddlers. It also seems likely that many of the well-qualified professionals will be operating in supervisory, rather than a direct service, roles in such programs. This is because the manifest shortages in these programs are sure to continue.

**Involving Higher Education in Personnel Preparation**. The next question posed by CPSP was, "If a shortage of qualified personnel is widely acknowledged, what are institutions of higher education doing to prepare to meet such shortages?" (Gallagher & Staples, 1990) Two-hundred forty nine Deans of Schools of Education were surveyed about any potential plans for expansion and what incentives would be needed to increase personnel resources. Less than half of the Deans reported a willingness to consider initiation or expansion of the programs for early childhood for children with disabilities, with many reporting that special programs within their universities were constricting rather than expanding. They reported major barriers in terms of lack of funding and lack of qualified faculty or practicum settings to train personnel in this special area.

In response to the question of what incentives would be useful to encourage higher education to be more active in this field, the Deans responded that some kind of additional financial support would be necessary. They also expressed a desire for evidence of a significant job demand in the field, along with some type of certification requirements that would indicate a continuing commitment of the state to this program area.

Without additional incentives or external support for personnel preparation, at least in the field of education and related areas, it seems unlikely that higher education will become active in a significant way in providing special preparation for their professional staff in work with infants and toddlers. In an additional policy alert, Gallagher (1989) pointed to the extended length of time taken to gain approval and to make operational new personnel preparation programs in higher education. The entire process of gaining approval in turn from faculty, department, school, and university, can take as much as 5-10 years. Gallagher concluded that steps should be taken early in the life of this law to expand development of personnel preparation resources for Part H. We should not, he concluded, wait for the other elements of planning and policy development to be completed.

**Professional Organizations' Role in Personnel Preparation**. The role that professional associations play in the personnel preparation area is well recognized. The Carolina Policy Studies Program embarked upon a survey of ten professional associations focusing on their plans for additional certification standards that might include services to infants and toddlers, the kinds of training initiatives that their association was planning in this area, and what concrete actions they were taking about existing personnel shortages (Gallagher & Coleman, 1990).

The findings from these questionnaires and follow-up telephone interviews indicated that only one of the ten professional associations (the Council for Exceptional Children) were encouraging the establishment of a special early childhood certification. Five of the ten organizations surveyed indicated that they would be developing guidelines of "best practice" for those of their profession who would be working with infants and toddlers. The remaining four organizations reported that they would not be developing additional personnel guidelines or recommendations for providing services to young children with disabilities.

All of the organizations were encouraging and supporting in-service training to upgrade the skills of existing practitioners and were setting significant time in their annual conventions to discussing this topic of infants/toddlers and their families. Many of the

professional groups felt that their training programs were already crammed full of topics and were resisting the addition of new courses or new curriculum material on infancy. They felt that they had reached a saturation point in extending their current training programs but anticipated attempts to incorporate material on infants and young children into their existing coursework and experiences (Gallagher & Coleman, 1990).

**Existing Staffing Patterns**. In order to determine what the current status of staffing programs were, the Carolina Policy Studies Program embarked upon an analysis of a major existing program of home-based early intervention services operated by the North Carolina Department of Human Resources (Palsha & Rennells, 1990). The study indicated that eight of the ten disciplines specified in the law were employed in this statewide service, with audiology and nutrition absent from the programs. The primary disciplines represented on the early intervention team were: special educators, psychologists, speech/language pathologists, and general educators. The allied health and medical professionals were generally employed as consultants on specific cases to serve a small number of children and families.

The substantial turnover in personnel in this program called for a continuing in-service training program to provide specific preparation for professionals moving into this program. The majority of personnel had either a bachelor's or a Master's degree, and did not meet the highest level of preparation in their particular discipline. If this program is representative of other programs around the country, then the level of preparation of staff personnel would be expected to be modest, and a continuing staff development program would be one of the strong necessities for future personnel preparation.

**Federal Agencies and Personnel Preparation**. In 1989, the Carolina Policy Studies Program assembled a focus group comprised of persons experienced in personnel preparation programs and posed a variety of issues for their discussion. Among these issues was the constructive role of federal agencies (Gallagher & Shields, 1990). Several recommendations emerged from these discussions, including a need to target post-doctoral leadership training for those who will "train the trainers," a priority given to in-service training, a request that the Federal Interagency Coordinating Council act to coordinate federal resources across a variety of agencies, the establishment of a national job bank, and the encouragement of foundations and other groups to assist in obtaining resources for personnel preparation. It was clear that the focus group felt that the federal government should be playing a more significant role, which would include providing a model of planning and coordination across agencies and disciplines.

**Statewide In-Service**. The same focus group that commented on federal agency participation also spoke to the issue of a comprehensive, statewide, inservice training program. Among the recommendations of this group was that a structure should be developed to promote a statewide comprehensive system of personnel development that would address all disciplines and levels of preparation. Such policies need to concern themselves with both entry skills and continuing levels of competency. They should include private service providers. Additional recommendations were that the multidisciplinary service model should be the unit of training and that such training should address service coordination and collaboration with families that are cross-discipline responsibilities. From this, there is a call for incentives for states to develop a system of in-service training. Gallagher (1993) proposed to set aside 15% of available Part H money for the state, to be invested in personnel preparation. This would be a means of stabilizing support for these programs (Gallagher & Shields, 1990).

**State Agency/Higher Education Coordination**. It was felt that a timely and effective response to critical personnel shortages required coordination between state agencies and

universities. Yet the experiences of many professionals in this field was that such collaboration was not the standard model of operation. Accordingly, the Carolina Policy Studies Program carried out a case-study approach on five states that had been nominated by early intervention experts as having demonstrated cooperation between higher education and state agencies in planning for personnel development. A structured telephone interview with participants in the Part H personnel planning efforts formed the basis for a report, along with a review of related documents (Rooney, Gallagher, Fullagar, Eckland, & Huntington, 1992).

Although each of the five states had unique histories and patterns for establishing this coordination, there were some attributes of successful collaboration that cut across the five states. One common denominator was what is referred to as a "bias for action," in which there were central events early in the stages of planning, such as collaborative conferences, that stimulated coordination and collaboration between personnel from higher education and state agencies. In addition, some formal structures were often put into place, such as consortiums of relevant higher education institutions, that addressed personnel preparation issues on a continuing basis. The key figures that played significant roles in these programs of coordination seemed to be process-oriented. They acted with foresight, and had a commitment to a vision or plan for personnel preparation. From these case studies, three major policy recommendations were generated:

1. States should form a consortium consisting of state agency, higher education, and professional organization representatives to address statewide planning for personnel preparation.

2. States should provide higher education with financial incentives (that is stipends and faculty funding) to increase personnel preparation programs.

3. Procedures should be established, such as a memorandum of understanding, to establish a semi-formal link between state agencies and higher education in terms of statements of mutual goals toward collaboration.

**Existing Personnel Preparation Models**. The Carolina Policy Studies Program was interested in identifying and conducting a case study on programs already existing to implement interdisciplinary personnel preparation. Three models were selected from a pool of nominations submitted by experts in the field of early intervention. These included the University of Illinois Preservice Masters and Doctoral Program in Early Childhood Special Education, the inservice efforts of the Wisconsin Personnel Development Project, and the leadership training institute for faculty involved in the preparation of family practitioners that was implemented through the collaborative efforts of the Center for Developmental Disabilities at the University of Vermont and Parent-to-Parent of Vermont Family Support Network. Six to ten key persons in each of these programs were interviewed with a semi-structured set of questions designed to draw information about the program's development, implementation, results, barriers and constraints, and future vision (Rooney, Fullagar, & Gallagher, 1992).

Once again, the programs seemed to take the form that fit the circumstances and personnel available. At the preservice program in Illinois, integration of content and process was emphasized and much of the interdisciplinary nature of the program was covered in field experiences and a seminar concurrent with that experience. In contrast, the inservice programs in Wisconsin were characterized by a widespread outreach effort utilizing multiple campuses and service delivery sites -- mainly because the training recipients were dispersed widely across the state.

Finally, the format of the leadership program in Vermont was based upon a concentrated, week-long institute (because that was the amount of time that could be made available by the faculty members). The faculty members received training from a variety of professionals brought in to provide support to the institute.

The significant barriers in these programs included such things as the departmental nature of a university system, which was referred to as "cumbersome." Turf issues were difficult to break down, even in interdisciplinary workshops and institutes -- although progress seemed to be occurring. A general lack of consistent financial resources made the training programs an adventure from year to year.

The policy recommendations which emerged from the study were:

1. Representatives of university and state agency systems should work together on an interdisciplinary consortium to plan and implement preservice and inservice personnel preparation efforts.

2. Courses should be team-taught to model the level of interdisciplinary collaboration needed in the field of early intervention.

3. Personnel developers should diversify funding sources to include federal, state, and private dollars.

4. Campuses within university systems should coordinate program requirements and honor each other's course work.

5. Certification procedures should be reviewed to determine whether existing procedures inhibit interdisciplinary personnel development.

Even in these three programs, which seemed to model an effective program, there were many barriers, constraints, and uncertainties. It is clear that personnel preparation needs to be stabilized in a continuing system that does not always have to depend upon the vagaries of grants or short-term contracts.

To state the obvious, a great deal more needs to be done in the personnel preparation area. While some states and programs have shown an admirable effort toward coordination and multidisciplinary participation, there is a need to systematize these programs and the support for them, so that support is not dependent on financial accidents or windfalls.

It is clear, on the basis of many studies (Rooney, Fullagar, & Gallagher, 1993; Arcia, Gallagher, & Serling, 1992), that progress toward full implementation will await an aggressive state policy on personnel preparation. Therefore, CPSP made the following recommendation:

> STATES SHOULD BE ENCOURAGED TO SET ASIDE UP TO 15% OF THEIR ALLOTMENT TO PROVIDE SUPPORT FUNDS TO INITIATE INTERDISCIPLINARY PERSONNEL PREPARATION PROGRAMS AND OTHER INNOVATIVE PROGRAMS DESIGNED SPECIFICALLY FOR THIS PROGRAM.

## Finance

*Sec. 676 (b)*

*(9) A single line of responsibility in a lead agency . . . for carrying out*

*(B) the identification and coordination of all available resources within the State from Federal, State, local, and private sources.*

*(C) the assignment of financial responsibility to the appropriate agency.*

*(11) a procedure for securing timely reimbursement of funds used under this part. . .*

The search for financial resources significant enough to provide support for the comprehensive, multidisciplinary, interagency service system for infants and toddlers with disabilities and their families is one of the most challenging of all of the requirements in IDEA.

**Method**. The Carolina Policy Studies Program (CPSP) approached this general topic area by use of state case studies, surveys of the fifty states, and calling upon the expertise of well-known figures in the financing of programs for children for their judgments on finance issues. Some of the questions posed were:

1. What are some of the options available to the states in financing this program?

2. What are the states doing now to coordinate financial sources -- federal, state, and private -- for the infant and toddler program?

3. What do the states see as potential future sources of funds for the program?

**Finance Options**. The fundamental issue faced by the states was that the federal government had mandated (if the states agreed to participate) an expensive program but had provided only funds sufficient to provide for program development and pilot work. The further suggestion from the federal law about how the program would be financed was that the states should attempt to pull together a variety of existing funds to pay for the new program. One serious problem was that the existing funds were already being used for a variety of other worthy purposes and could not easily be diverted to the infant/toddler program.

Clifford (1991) reported that the states were experiencing substantial gaps between available resources and the funding of service needs; and this was during the early stages of service provision. At that time, Clifford proposed three possible strategies to deal with the issue: (1) Fund all Part H services under Medicaid; (2) Earmark portions of each major piece of federal legislation affecting children to assign funds for Part H services; or (3) Transform Part H into a new funding entitlement for services for infants and toddlers with disabilities and their families.

Kastorf (1991) elaborated on the option of Medicaid by describing, in some detail, the Massachusetts experience with this program. Kastorf believed that Medicaid is a feasible alternative although there are issues to be confronted with its use, such as: the state's matching funds, interagency coordination, and especially the need to define precisely early intervention services so that they can fit into the unit-rate purchasing system of Medicaid.

Van Dyck (1991) also reported on the possible use of parental fees in P.L. 99-457 Part H. He presented six options, ranging from totally free care to combined the use of medicaid, private insurance, and a sliding fee scale for parents, together with the advantages and disadvantages of each of the six options. Van Dyck thinks that a financial solution is best obtained in those states where Part H is under Health services, and where there is a history of payments from Title V of the Social Security Act and Medicaid.

It seems unlikely, in the extreme, that parents' fees could add substantially to the total sum of money needed to pay for this program. For one thing, many of the parents are poor and can afford to pay only a pittance towards the real costs. Also, the total costs for many children who are medically fragile can exceed any parents' ability to pay. The use of parents fees can really be seen as a moral or psychological issue relating to personal responsibility, rather than one with significant financial consequences.

**Finance Coordination**. Finally, Clifford, Bernier, and Harbin (1993) completed a survey of the states on their current strategies for financing Part H. While they found states using an aggregate of 44 different sources, most states were concentrating on three main sources for the majority of their dollars. About half of the sources were other federal programs (e.g., Title V of the Social Security Amendments), one third were state/local, and the remaining sources were non-governmental.

**Future Sources of Funds**. With regard to funds that states anticipated increasing in the future, the major options that were considered as possible for increased funding were: Early Periodic Screening Diagnosis and Treatment (EPSDT), Medicaid (federal), Chapter 1/handicapped, Part H, Private Insurance, Medicaid (state match), and the state Mental Retardation and Developmental Disabilities program.

Clifford, Bernier, & Harbin (1993) recommended the following:

1. States should continue to focus on Medicaid as a source of financing Part H services.

2. States should also focus on state sources.

3. States should broaden their focus to include more sources.

4. States should work with federal agency personnel and Congress to develop a more coherent, simplified approach to financing Part H services.

5. A new federal approach to financing Part H should be developed and implemented.

On the grounds that continued financial uncertainty can seriously undermine the program, CPSP made the following recommendation (Gallagher, 1993):

> ALL CHILDREN JUDGED ELIGIBLE FOR PART H SERVICES SHOULD AUTOMATICALLY BECOME ELIGIBLE FOR MEDICAID FUNDS WITHOUT AN INCOME TEST.

The rationale for such a provision is that the expenses often incurred when raising infants and toddlers with multiple disabilities becomes so great -- even for very high income families -- that it makes the assumption of "ability to pay" a mockery. Instituting a provision such as the above would place the program on solid financial footing and would also guarantee significant contributions from the states through matching provisions of Medicaid.

One of the most basic of messages from these CPSP finance studies and surveys was that the original plan for financing this Part H program could not work and needs to be replaced with a strong plan involving both state and federal dollars that could be counted upon over time. This still has not happened, as of the date of this report.

**Interagency Coordination**

*676 (B)*

*The Statewide System will include:*

*(B) The identification and coordination of all available resources within the state from Federal, State, local, and private sources. . . .*

*(D) The development of procedures to ensure that services are provided to handicapped infants and toddlers and their families in a timely manner pending the resolution of any disputes among public agencies or service providers.*

*(E) The resolution of intra and interagency disputes.*

*(F) The entry into formal interagency agreements that define the financial responsibility of each agency for paying for early intervention services (consistent with state law) and procedures for resolving disputes that include all additional components necessary to ensure meaningful cooperation and coordination.*

It has been obvious to the various professional communities for some time that a comprehensive service system for infants and toddlers with disabilities will require a substantial restructuring of existing agency programs and interactions (Harbin & McNulty, 1990). A single child and family could conceivably have serious problems requiring attention from the health, social services, education, and psychology domains. In addition, there would need to be cooperation among these disciplines to build an effective infrastructure for the service system (e.g., personnel preparation). However, in order to satisfy the mandate of the federal law and provide effective program coordination at the local and state level, there has to be substantial negotiation between agencies that already have a major stake in service delivery for children.

The Carolina Policy Studies Program posed three major questions that were to be answered through a series of policy studies. These questions were:

1. How will the Interagency Coordinating Council work to improve state agency coordination?

2. What kinds of structures and processes are the states providing to facilitate coordination?

3. What are the kinds and nature of interagency agreements which the states have entered into?

**Method**. To answer these and other questions related to interagency cooperation, CPSP used a series of six state case studies in which semi-structured interviews were carried out on-site with a variety of state agency personnel and representatives of higher education and advocacy groups. The legislation itself was analyzed through reference to a literature review, and finally a fifty state survey of the Part H coordinators was carried out focussing on finance and interagency coordination.

Interagency Coordinating Council. Early case study analyses, as well as early inquiries of NEC*TAS, revealed a lack of clarity regarding the role and responsibilities of the ICC. CPSP produced a policy alert related to the roles and responsibilities of the ICC (Harbin & Van Horn, 1990). The law itself specifically gives the ICC authority to advise and assist the lead agency with functions such as:

* The identification of sources of fiscal and other support for services;
* The assignment of financial responsibility to the appropriate agency;
* The promotion of interagency agreements; and
* The preparation of applications and amendments.

In addition, the federal regulations expanded the responsibilities of the ICC to include: advising and assisting in the development of policies; assisting in achieving full participation, coordination, and cooperation of all appropriate private and public agencies; and serving as a trouble shooter for unresolved policy problems and resolution of disputes.

Harbin & Van Horn (1990) presented a series of possible ICC roles to be played, under three major headings: developing written policies, getting policies accepted and adopted, and facilitating the smooth operation of a service system. Many sub-roles can be identified under these major areas, and much of the early difficulties in the functioning of the ICCs seemed to relate to the multiplicity of tasks that they were assigned or which they chose to address.

The CPSP study concluded that the level of authority for each state's ICC seemed to fall on a continuum that ranged from a passive role -- in which ICC provides advice only on topics raised by the lead agency -- to actually acting more as a Board of Directors, with policy-making authority. Some of the early and continuing problems within each state that remained were the dynamic relationship between lead agency and ICC and the effective division of roles and tasks between them. In many states, there appeared to be a solidifying of the roles of each organization.

Structures for Coordination. Case studies of six diverse states examined the factors that facilitated the coordination of services and policies across agencies. One of the most important findings was that there appeared to be strong leadership with decision-making authority in some states that were actively engaged in developing an interagency vision of new relationships. These individuals tended to lead through participatory decision-making by providing a framework for the vision of a comprehensive service system and, above all, by showing the ability to gain trust from a diverse set of constituencies. These leaders seemed to be accomplished in the art of negotiation and were often described as "bridge-builders" or "fence menders." It is the establishment of a sense of trust that allows the other agencies to participate without fear of being taken advantage of.

The early structures and mechanisms for interagency coordination included a series of task forces or committees across agencies, with key division chiefs or responsible staff participating in planning for effective coordination. The personal relationships which established a level of comfort and trust were key factors in the process toward final formal agreements. A number of informal agreements were made in states before formal documents were produced.

It was stressed in the early state case studies, however, that coordinated planning requires significant staff time. There must be time allotted to allow the complex process of

interagency coordination to go forward, and the states that appeared to be performing well were able to provide that released time. One of the key factors that allowed a number of states to go forward was prior experience with interagency coordination. While some states had little or no experience at formal or informal agreements across agencies, others seemed to have had years of experience at it and were thus able to move forward on this topic with relative ease.

Some of the CPSP recommendations related to interagency coordination were:

1. There is a need for a structured planning process.

2. There is a need for multi-level interagency structures -- the ICC cannot do it alone.

3. There is a need for a liaison between agencies to ensure coordinated planning and policy development.

**Scope of Interagency Service Coordination**. While it was encouraging to find progress being made in the six state case studies, questions remained about how widespread these efforts at coordination were in the other states. Accordingly, a survey was sent to all Part H coordinators dealing with finance (previously reported) and interagency coordination. This interagency survey was designed to describe the nature and scope of service coordination by finding to what extent, and of what kind, agreements were being made in the fifty states. Thirty eight of the fifty states responded to the questionnaire, and the results were considered encouraging by the authors of the CPSP report (Clifford, Bernier, & Harbin, 1993). What was evident from the survey was the widespread commitment of personnel in agencies in states throughout the country in implementing the coordination aspect of Part H. Many states indicated that they were coordinating with other relevant programs (EPSDT, Maternal & Child Health, etc.). Many states were coordinating efforts to serve at-risk children.

Other states were combining Part H efforts with a wider state initiative to serve all young children. It was something of a surprise to find that 57% of responding states were actually changing their more general policies to be more complementary with the early intervention policies of Part H. By the time the survey was completed, there had already been substantial efforts at service coordination. The mean number of agencies involved in service coordination at the state level was 4.8 and the mean number of programs involved in coordination efforts was 10.35. Generally, more agencies were involved with systems entry activities such as child find and public awareness, and fewer agencies were involved with coordinating developmental intervention, planning, or therapeutic services.

One of the common structures used to enhance the coordination effort was to identify persons to act as liaisons between Part H and the activities of the other agencies. In addition, 70% of the responding states had created interagency work groups to facilitate service coordination; 78% of the states utilized groups of division directors to plan and negotiate policies related to the Part H population.

In addition to the states constructing a number of formal interagency agreements, they were also encouraging such agreements at the local level, as well. The study concluded that there was a widespread commitment of agency personnel to the concept of service system coordination. Many agency programs and service providers have been deeply involved in the development of policies and processes related to service coordination. Those who may have thought that the states would give only passing lip service to this issue were quite mistaken.

Such changes as the states made, however, in the relationship between agencies and the role of state versus local government did not come without a price. The state case studies indicated that the greater the rate of change in state policies regarding the design of a delivery system for children and families with disabilities, the more difficulties were experienced in gaining a consensus. States that modified their current policies and procedures only slightly did not have the same level of discussions or negotiations to make -- nor did they engage in as many activities (state conferences, outside consultants, task forces, etc.) -- as did the states seeking substantial change (Harbin, Clifford, Gallagher, Place, & Eckland, in press).

However, the states that made moderate or major changes in the structure of their state government may be more satisfied in the long run. The literature of change seems to suggest that unless structural changes take place during the change process, the modifications that are intended may not last and procedures and organizations are likely to drift back toward the previous status quo.

It remains to be seen, however, how the coordination actually works once the service system is in full operation. Undoubtedly there will be situations that have to be modified and adapted, as experience indicates problems. One of the things that this program for infants and toddlers and their families appears to have done is to convince state agency personnel that they must engage in interagency coordination if they were to provide the services to the clients that each, in their own individual set of responsibilities, would want to do.

## Health Coordination

*Sec 672 (E)*

*Early intervention services include:*

*(x) health services necessary to enable the infant or toddler to benefit from the other early intervention services.*

The law for infants and toddlers with disabilities and their families has stressed the importance of interdisciplinary cooperation. One of the fundamental questions that was posed by the law concerned how to bring together the operating health systems from both the private and public sectors and the early intervention professions focussing primarily in education and social work. This question was particularly important in view of the limitations that have been set in the law regarding participation of health personnel. As seen above, the health sector, within this law, is limited to the provision of services deemed "necessary" for educational and intervention services (e.g., catheterization).

**Health Policy Coordination Questions**. There were three major policy questions posed in the studies conducted by the Carolina Policy Studies Program. These were: (1) what involvement do physicians have in planning for the implementation of the infants and toddlers law? (2) What are the major factors or forces preventing more effective coordination of health services with early intervention services? and (3) What are some options or solutions to the problem of cross discipline cooperation and coordination?

**Method**. To answer the first question on physician involvement, a survey was designed and presented to all physicians who were participating on the Interagency Coordinating Council in each state. Additional members were added who served as state chapter representatives to a key conference of the American Academy of Pediatrics on this law. A total of 125 physicians completed the survey from a total sample of 146.

To answer the second question on barriers to effective coordination, a total of 10 focus groups were assembled and conducted -- two in each of five states. These focus groups tried to identify the major inhibiting forces at work that limit service coordination from the health perspective. Health personnel from both the private and public sector were identified and participated. Sixty-five percent of the participants were pediatricians and neonatologists. Sixteen percent were nurses or physician assistants. The remaining 17% were physicians with specialties not related to young children.

**Policy Involvement of Physicians**. The survey on physician involvement found a keen interest in commitment to the program among the core group of physicians. However, six states had no physicians involved in working on their ICCs and twenty-four states had no private, community-based practitioners on their ICCs. The physicians themselves were strongly in favor of a strong eligibility criteria that would include both children with biological risks and environmental risks. The physicians also reported a modest improvement in the relationship between private health care sector and the public human services system since the enactment of the infants and toddlers law. These physicians felt that the major barriers to full implementation of this law were:

1. The low level of funding and current reimbursement policies.

2. A lack of interagency/practitioner coordination; problems of "turf" and difficulty of referral.

3. The lack of appropriately trained personnel and the shortage of appropriate services.

The CPSP report (Wenger, McLauren, Guild, Loda, Gallagher, DeFriese, Rich, & Bergsten, 1989) pointed out how important it was to develop and provide support for structures for physician participation in planning and coordination of this program at the local level.

**Inhibiting Factors to Health Coordination**. In the focus group discussions on barriers to effective coordination, health care providers were invited to participate who had been recommended by parents and professionals involved in programs for young children with disabilities (Fullagar, Crotser, Gallagher, & Loda, 1993).

The results obtained from the ten focus-group discussions covered a wide range of issues related to coordination, the relationship between professionals, and between professionals and clients. Three major themes emerged from the discussions of coordination difficulties between health providers and human service providers.

1. Shortage of professional resources

2. Importance of service coordination

3. Family and social issues.

**Professional Resources**. With regard to the shortage of professional resources, specific comments were made about the lack of available community-based care programs which tends to delay the release of medically fragile children from tertiary care centers. The report also indicated difficulty in locating non health-care providers who had the necessary expertise to cope with these children. They expressed frustration over the turnover of such personnel and their own inability to evaluate the quality of care provided once they had referred the patient to other professional services. Two other issues related

to resources were insurance coverage and transportation. There was a general feeling that the Medicare coverage should be available across all Part H services and that there should be some systematic program to allow for transportation of the family to the treatment centers or private physicians.

Service Coordinator. It is clear that the role of the service coordinator (formerly "case manager") is far from settled. From the health perspective, several models were seen, including: the physician as coordinator, the physician as medical coordinator, and the physician as consultant to a multidisciplinary team. Basically they describe the service coordinator role at two levels in the health services area. The first level is the executive or decision-making level. On this level, the leader of a health team decides what treatments should be provided to the client and in what order. On another level, and presumably done by another person, there is a management coordination role in arranging for contacts with the family and in bringing together the various threads of information related to the family, particularly in a multidisciplinary setting. This conceptualization of the service coordinator seems substantially different from the human services concept, and it is likely to continue to be a problem across disciplines until some agreement is reached with regard to the essential role-functions of this key player.

Family and Social Issues. With regard to family and social issues, the health providers were sensitive to the pressure that the constant care of an infant and toddler with disabilities places on parents. Once again they stressed the importance of day care and respite care that was provided through highly skilled staff members. They also discussed the problem of the family in poverty and associated difficulties that can aggravate the situation for the child with disabilities. In particular, transportation seems a huge barrier to the access of health care for the poor, the working poor, and for teenage parents.

The health providers felt that families who were stressed by many layers of difficulties may need assistance with these other issues in order for health personnel to be effective in their care of the child who was disabled. They discussed the unintended consequences of some of the Medicaid rules which limit the reimbursement of psycho-sociological support which should otherwise be provided.

These overall findings did not vary significantly from one focus group to another, although certain issues (such as transportation) were stressed more in rural than in suburban or urban groups. While the focus groups yielded large numbers of eloquent statements regarding the problems, they also generated relatively few ideas about solutions.

Health Policy Alternatives. To answer the third question regarding possible options for improving coordination, the Carolina Policy Studies Program commissioned a series of papers that were presented in a working conference in Washington DC by experts on various topics related to the coordination of health services. Papers were requested that would provide ideas related to solutions to coordination problems on both individual and systemic issues. The contributors to this conference also produced written papers that were presented in one of the CPSP publications (Gallagher & Fullagar, 1992). All of the contributors in one form or another called for a series of structural changes in service delivery and formal systematic coordination as part of their solutions for their coordination difficulties. Hutchins (1992) stressed the broad and unconnected history of legislation in this area, resulting in gaps and fissures and a lack of coordination across disciplines. Shonkoff (1992) recommended the development of a family-centered, community-based system of primary care serving all children, without regard to specific eligibility or identification of particular problems or needs. He believes that attempts to bypass the health care system in the establishment of an independent network of family-centered service programs may undermine the skills and long-term contributions of health care

providers. He believes that the health care system should play a much more central role in the overall treatment programs of these youngsters.

Walker (1992) also stressed the importance of a family-centered early intervention system -- but one in which the health care community plays a central role. Walker also emphasized the integration of family-centered care concepts into all of the professional preparation programs in medical, educational, and allied health. Magrab (1992) reminded us of a continuing crisis in the delivery of early intervention services in rural areas; she believes that full-time case managers could bring together an interdisciplinary care program for families. Child-find activities become even more important in rural areas, where the affected children may not be under continued observation by others.

Kochanek (1992) stressed the importance of developing experimental and demonstration programs that encourage coordination and technical assistance and provide systematic alternatives to the existing system. Finally, Gallagher (1992) reminded us that the literature on organizational change has revealed that reforms tend to regress back to the status quo unless they are accompanied by structural changes that permanently modify the status quo. He proposed a community family-service center, not unlike those suggested by Shonkoff and Walker, that would be staffed by multiple disciplines and would represent a "one-stop shopping center" for health care and intervention services. Such a program could be supplemented by home-based care systems, particularly in rural areas, where transportation to the centers becomes a major obstacle.

The various studies on health coordination by the Carolina Policy Studies Program make it clear that the Part H program is a long way from settled on how to constructively interrelate health services with other human services. There is a widespread belief that a new structure of health services, stressing coordination and multidisciplinary cooperation is necessary and that many people will be working toward such a goal in the immediate future.

## Data Systems

One of the fourteen dimensions required of the state to reach full implementation of this law was the establishment of a data system. This is clearly part of the program infrastructure that may become evident to the professional or the family only when they have to fill out forms or respond to data requests of one sort or another. Data systems was one of those components which the states were slowest to implement into policy (Harbin, Gallagher, & Batista, 1992).

The questions regarding data systems asked by the studies of the Carolina Policy Studies Program were:

1. How were states planning to use data systems to improve their program development?

2. How were local communities planning to use data systems to improve performance?

3. How can data systems be used to ensure full participation by various societal subgroups?

**Method**. The continued unavailability of many state planning efforts in this dimension led to a study of subsets of states that *had* taken action in this area (Hebbeler, 1993). Using documents and phone interviews, CPSP was able to examine the data systems of eight states in some depth.

**State Use of Data Systems**. The federal requirement for a data system was clearly an attempt to gather information to determine whether the basic goals of the legislation were being met. A secondary goal was to collect information that would allow states and the federal government to make changes in policies or operations to improve the functioning of the comprehensive service system.

One real question was whether such a data system was, in fact, being established in the states. Is this just one more onerous requirement set forth by the federal government upon the states in exchange for some additional resources promised by the federal government? If the states felt that way about it, would they not be likely to establish some type of reporting system to satisfy the lowest level of federal government requirements with little regard to whether the system had a strong relationship to the real world of the service system, or to the generation of data that actually influenced state or local policy decisions?

Hebbeler's review of eight states with extant data systems came to a different conclusion (Hebbeler, 1993). Hebbeler found that the states had multiple purposes in mind when designing a data system (which, in many cases, was an extension or adaptation of systems already present at the state level). The study revealed three ways in which state-level administrators were using their early intervention data systems: (a) overseeing local programs, (b) automation of the process of billing for services, and (c) an approach to meet federal reporting requirements.

The state has many different sets of information that it needs from local service providers. States wish to know how many infants and toddlers are being served. They wish to have cost information for future planning. Such information can identify holes in the service delivery system, where certain services may not be available, or are being provided too slowly, or can identify an absence of trained personnel.

The data system can be used to plan for the future -- projecting, for example, how many children need to be served. The data system can facilitate connections across agencies and institutions. Finally, it is a source of information for legislators, governors, and other public decision makers who want to know what is happening in the programs they have funded and supported (or opposed).

Billing for services is one of those very practical elements of a program, yet one that can often cause great frustration. The call in this legislation for policies leading to "timely reimbursement" is, in some measure, a plea precipitated by past experience of untimely reimbursement. A state-level, client-based data system can help facilitate some of the connections across agencies and institutions and can track families from one service program to another so they don't "fall through the cracks."

Some states seem to be trying to merge existing data systems, some merely wish to link existing systems, while other states wish to build a new comprehensive data system that will integrate information from a variety of agencies at the state level. Each of these strategies appears to work for particular states, given the context in which they are operating.

**Local Use of Data Systems**. The advantages that local service systems could extract from a state data system would be that they could do one or more of the following:

- Generate statistical reports on clients for planning and evaluation purposes.
- Review data and produce various subsets of children.

- Monitor the status of services to individual children and families.
- Produce legible, complete copies of a child's record, including the IFSP, for sharing with the family, other staff, and other community agencies.
- Access information about other resources available in the community.
- Generate individual transition reports for school districts that will be coping with these children in a short time.
- Easily and quickly transmit required data to the state.

All of this assumes that such information is in the local program's database, which may often be adapted for local use.

**Full Participation of Special Populations**. One earlier question that has received considerable attention has been how the state data system can be used to determine whether services are being delivered to certain subpopulations that have been traditionally underserved. For example, a state with a statewide population of 30% Latino families would hardly be expected to have less than 30% Latino children in the service delivery system, because low income and minority status can typically be counted upon to produce more than its share of children with special problems. If only 15% of the population being served under Part H is Latino, then this should trigger an alarm bell and the Child Find part of this program should receive special instructions.

This scenario, however, depends upon whether or not the state collects the information necessary to make such determinations. In a study of 16 states (Arcia & Gallagher, 1992) using telephone interviews and documents, it was discovered that 10 of the 16 states collected information on ethnicity or race, but six did not. In those states that did not collect full information, the data would not allow for the simple analysis noted above.

Only two of the states collected data on family income. Arcia & Gallagher(1992) made several recommendations:

1. Clients should be identifiable by race and/or by ethnic background.
2. Family income, at least to 200% of the poverty line, should be noted.
3. Families should be identifiable by place of residence (zip codes are a convenient option).
4. Parent employment and insurance coverage should be noted.

Such information is a prerequisite for gaining insight on the issue of who is being served by the system.

## Discussion

There are a number of general observations made by the CPSP staff in the process of conducting these multiple policy studies that need some additional comment. The first is the strong impression of the "good faith" effort that the states have generally made to implement this complex law. The rewards from the federal government in terms of financial support were not impressive, and the tasks that had to be accomplished were

daunting and complex, requiring the modification of many of the practices and policies that the state had, in the past, been following. This implementation had to be carried out during a period in which many of the states were experiencing serious fiscal downturns or even crises. The temptation had to be great to put this new law aside in favor of salvaging programs threatened by the fiscal situation. Despite these potentially negative forces, our impression through the multiple policy studies that we conducted is that there were a large number of people in each state who felt that this was an important program; one that needed to be put into place.

This law has been referred to as revolutionary in tone. such a term has been used because of the many different changes proposed in the states' personnel preparation standards, interagency coordination, family empowerment, expanded data systems, and financial responsibilities.

Yet the states, in their responses to the law, have not treated it as revolutionary but, rather, as evolutionary. The states have, in large measure, attempted to embed the new procedures into the existing structure. When changes have been suggested, such changes are often built upon the current systems or extensions of the current procedures.

It was asking too much of such a relatively small law, commanding only a miniscule part of the state budget, to be the fulcrum for major state reform. Still, the evolutionary nature of the changes that were taken did seem to be well-received by the professionals and by the state agency leadership personnel, who considered them for the most part necessary and constructive.

**Ideas Whose Times Have Come**

There was, in fact, a strong sense that the changes that the law were requesting were long overdue. There were no sustained protests in the states about the requirement for interagency coordination, because it was easily accepted that some cooperation and coordination was necessary if a comprehensive, multidisciplinary program of services were going to be delivered. Similarly, the parent empowerment aspect of the law, while burdensome in some situations, was also widely accepted as good practice that would pay off in improved performance by both children and families. The recommendation for multidisciplinary personnel preparation programs was another topic that was generally seen as positive -- at least in principle. The problem in all of these instances was that despite the generally positive attitudes that professionals and non-professionals alike had toward these changes, there was a lack of specific knowledge and technical know-how about how to accomplish these goals. The basic problem was not in the will to do it, it was in the skill to do it. Part of the reason for the slowness of implementation is that even after some people learned how to be skillful in accomplishing these new goals, large numbers of other people had to be instructed in the process in a similar fashion.

One can only imagine what chaotic conditions would have prevailed if the basic principles in the law had run counter to local values and intentions. In this regard, the flexibility that the law provides for state and local communities to carry out these mandates according to the local circumstances was probably one of the saving graces that allowed the states to proceed.

**Unsolved Problems**

Despite the evident progress that was made by the states in implementing this law, there were many policy issues that remained to be solved in the immediate or near future.

**Service Coordination**. Many of the troublesome issues were put on hold or finessed by decision-makers at the state level in order that a basic set of agreements and actions could be settled upon. For example, there remains the issue of the service coordinator, whose role and authority continues to be shrouded in mystery and uncertainty. It is likely that this role will have to be hammered out through a long series of direct experiences with service delivery.

**Interdisciplinary Training**. Similarly, although there is a general acceptance of the principle of interdisciplinary training, there are remarkably few efforts at attempting to put such personnel preparation programs into place. This situation is not helped by the structural problems in higher education, where cross-departmental programs and cooperation are not accepted practice.

**Finance**. Above all, the finance situation remains uncertain. The one thing that seems clear is that the original plan of paying for the program by pasting together a variety of funds available at the state level is not going to work. Some alternative must be found if the program is to evolve into the next phase of full service delivery. The CPSP staff generally favors the use of Medicaid for all eligible children as one viable solution, but this solution would be dependent upon the current national planning efforts to provide an overall health care system for all citizens. If the Medicaid solution does not work, then some direct funding by the state would seem to be an alternative, although a difficult one to achieve during these times of continued state problems with budget-balancing and reluctance to seek additional funds through taxes.

**Diversity and Policy**. One other suggestion made in one of the policy studies merits some additional attention here. That is the problem that is inherent in writing policies for a diverse group of citizenry. The population that is to be served here varies along many dimensions: socioeconomic status, type and intensity of disability, geography and availability of resources. Writing a set of rules that covers all of the diverse situations of all of these people presents something of a challenge, which was met, in part, in the original law by allowing flexibility in how to execute the program at the state and local level. One of the inhibiting forces to that flexibility, however, is the continuing process of inquiry by states and the subsequent legal interpretation, which is the responsibility of the federal agency, OSEP.

Each time there is puzzlement at the state level about what "such and such" provision of the law or regulations means, there is a tendency to write to the federal government for an official interpretation of what was actually meant by this phrase or this clause. The federal answer takes the form of a type of "class action" suit, in the sense that it answers specific cases with a general principle that will apply to everyone concerned. The successive effect of such inquiries and interpretations is a progressive limiting of the flexibility of the law. Gallagher (1993) suggested an alternative to this tightening process. With regard to the specific issue of eligibility, he proposed that there should be an allowance of up to 10% of cases that could be found eligible by the clinical judgement of a team of qualified professionals, even though the child might not appear to meet the specific criteria of eligibility as set by the state.

There are certainly individual cases that would defy any set of standards that could be established and, yet, in the judgement of professionals clearly should be eligible for services under this law. Attempts to write and rewrite regulations to fit all of these diverse and unusual cases and circumstances has the long-term effect of tightening the law and making it less flexible. The alternative -- use of properly limited clinical judgement -- would seem to have enough merit to be attempted.

The final proof of the usefulness of this law will lie in the actual service delivery which, as this report is being written, is in its initial stages in many states. It is fortunate that another Child Development Institute has been supported by OSEP to track the implementation of the law in the policy application phase of implementation. The findings from that institute should substantially supplement the findings from the Carolina Policy Studies Program and provide useful policy information for the states and for the federal government in continuing to create the conditions for quality services to be delivered to infants and toddlers with disabilities and their families.

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# APPENDIX A

## CPSP References by Year *

1993

Arcia, E. & Gallagher, J. (1993). Recommendations for State Data Systems, The Importance of Socioeconomic Variables.

Arcia, E., Keyes, L., Gallagher, J., & Chabhar, M. (1993). Status of Young Mexican-American and Puerto Rican Children: Implications for Early Intervention Systems. This paper contrasts the number and amount of problems being experienced by Mexican and Puerto Rican families as revealed by some major demographic data bases. The implications for Part H are explored.

Clifford, R.M., Bernier, K.V., & Harbin, G.L. (1993). Financing Part H Services: A State Level View. The results of a survey of state coordinators of Part H on the current and future finding of Part H.

Fullagar, P.K., Crotser, C., Gallagher, J., & Loda, F. (1993). Communication, Coordination, and Cooperation: Perspectives on Service Delivery and Part H. Fullagar summarizes a major study of health personnel and their views on the coordination of services of the health community with other service providers. Focus groups in five states were used to determine the major issues regarding coordination.

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Harbin, G., Clifford, R., Gallagher, J., Place, P., & Eckland, J. (in press). Systems Change: Case Studies of Six Diverse States.

Hebbeler, K. (1993). Data Systems In Early Intervention. A detailed description of the development of data systems for early intervention programs in eight states. An encouraging sign was that many of the states were using the data systems to improve decision making at the state level and going far beyond merely responding to federal requirements for data.

Rooney, R., Fullagar, P., & Gallagher, J. (1993). Distinctive Personnel Preparation Models for Part H: Three Case Studies. A report of a telephone survey of five states on the coordination of program efforts between state agency and higher education in those states.

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**Arcia, E., Gallagher, J.J., & Serling, J. (1992).** But What About the Other 93 Percent?

**Arcia, E., Keyes, L., Gallagher, J., & Herrick, H. (1992).** Potential Underutilization of Part H Services: An Empirical Study of National Demographic Factors. A paper dealing with the possible underutilization of Part H services with certain vulnerable subgroups in the society.

**Arcia, E., Serling, J., & Gallagher, J. (1992).** Review of State Policies to Empower Families and Reach Populations Typically Underserved. An analysis of a subgroup of states to determine if state policies have the specificity necessary to reach typically underserved populations.

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**Paul, J.L., Gallagher, J. J., Kendrick, S. B., Thomas, D.D., & Young, J.F. (1992).** Handbook for Ethical Policy Making. A multiple author handbook devoted to the ethical issues that are encased in Part H of IDEA. It reviews the various issues that have strong value orientation and provides a model for coping with such issues.

**Place, P. & Gallagher, J. (1992)** Part H Policy Development for Families: A Case Study Report.

**Place, P.A. & Brown, Carole (1992).** Trust, Entitlement, or Some of Both: Can the Part H System Provide the Supports Families Need and Want? A report on the diversity of policy related to the family in three separate states.

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**Clifford, R.M. (1991).** State Financing of Services Under P.L. 99-457, Part H,. Report of first year case studies of financing in six states.

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**Harbin, G., Danaher, J., Bailer, D., & Eller, S. (1991).** Status of States' Eligibility Policy for Preschool Children with Disabilities. Report presenting results of an analysis of current status of states' eligibility policies for children with disabilities, age three through five.

**Harbin, G., Eckland, J., Gallagher, J., Clifford, R., & Place, P. (1991).** State Policy Development for P.L. 99-457, Part H: Initial Findings from Six Case Studies. A report which summarizes preliminary findings from a six state case study analysis of the implementation of Part H, IDEA. The framework for approaching the case studies is also presented.

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**Harbin, G.L. & Terry, D.V. (1991).** Interagency Service Coordination: Initial Findings from Six States. Report presents findings from the first year of a multi-year case study of interagency service coordination with regard to implementation of Part H of IDEA.

**Harbin, G.L., & Maxwell, K. (1991).** Progress Toward Developing A Definition for Developmentally Delayed: Report #2. Report describes states' eligibility policies for developmentally delayed and at-risk children, aged birth to three.

**Harbin, G.L., Gallagher, J., & Lillie, T. (1991).** Status of States' Progress in Implementing Part H of IDEA: Report #3. Report summarizes progress made to date, as well as progress made from 1990 to 1991 by the states in policy development, approval, and application, and includes suggestions for encouraging continued participation.

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**O'Reilly, F., Place, P.A., & Anderson. (1990).** Individualized Service Plan: A Comparison of Major Federal Programs Affecting Infants and Toddlers with Handicaps and Their Families. An excerpt from the digest and comparative analysis by the same authors with an emphasis on individualized service plans.

**O'Reilly, F., Place, P.A., & Anderson. (1990).** Parent Training: A Comparison of Major Federal Programs Affecting Infants and Toddlers With Handicaps and Their Families. Excerpt from the digest and comparative analysis by the same authors with an emphasis on parent training.

**O'Reilly, F., Place, P.A., & Anderson. (1990).** Procedural Safeguards: A Comparison of Major Federal Programs Affecting Infants and Toddlers With Handicaps and Their Families. Excerpt from the digest and comparative analysis by the same authors with an emphasis on procedural safeguards.

**O'Reilly, F.E., Place, P.A., & Anderson, K. (1990).** Advisory Councils: A Comparison of Major Federal Programs Affecting Infants and Toddlers with Handicaps and Their Families. Excerpt from the digest and comparative analysis with an emphasis on advisory councils.

**O'Reilly, F.E., Place, P.A., & Anderson, K. (1990). Identification and Evaluation: A Comparison of Major Federal Programs Affecting Infants and Toddlers With Handicaps and Their Families.** Excerpt from the digest and comparative analysis by the same authors with an emphasis on statutory wording regarding identification and evaluation.

**O'Reilly, F.E., Place, P.A., & Anderson, K. (1990). Case Management: A Comparison of Major Federal Programs Affecting Infants and Toddlers with Handicaps and their Families.** Excerpt from the digest and comparative analysis by the same authors with an emphasis on case management.

**Palsha, S. A. & Rennells, M.S. (1990). Staffing Infant Intervention Programs: One State's Status and Future Direction.** A review of the type of personnel employed in early intervention programs in one statewide home intervention program.

**Place, P., Gallagher, J., & Harbin, G. (1990). State Progress in Policy Development For the Individualized Family Service Plan (P.L. 99-457, Part H).** Report presenting results of a survey of states; existing policies with regard to IFSP and states' intended plans for further IFSP policy development.

**Yoder, D. E., Coleman, P.P., & Gallagher, J. J. (1990). Personnel Needs - Allied Health Personnel Meeting the Demands of Part H, P.L. 99-457.** Report outlines technical problems that state planners may face regarding personnel needs for Part H.

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